

**DE-INSTITUTIONALISATION OF PEOPLE WITH LEARNING
DISABILITIES, ORGANISATIONAL CHANGES AND THE IMPACT ON
PROFESSIONAL ROLES**

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ABSTRACT

This study explores the development of a discharge programme in one learning disability hospital in Scotland. The aim of the study is to explore professionals' perceptions of how the discharge programme developed with a focus on capturing professionals' experience and knowledge so as to reach an understanding of how best to facilitate a discharge programme and help professionals make the transition from the institution to the community.

Different groups of professionals were interviewed and different views and perspectives regarding the progress of de-institutionalisation were collected. Based on the professionals' perceptions and with a particular emphasis on those of social workers, the following issues were identified as the key points which have to be taken into account for facilitating stable progress in a discharge programme: the creation of a consortium with centralized authority which includes the establishment of a formal process and joint working between health and social work, the setting up of a so-called "stakeholder" management model, the implementation of specific practices and policies with regard to the actual discharges and arrangements for enhancing professionals' adaptability.

INTRODUCTION AND PURPOSE OF THE STUDY

The current thesis is a study of de-institutionalisation. The case of an institution for people with learning disabilities was put under scrutiny and this study concentrates on organisational developmental changes in this institution. This is a case study, examining organisational changes in a specific organisation, during the implementation of a discharge programme. Two main factors motivated me to be involved in such a topic. The first factor was that the welfare state in Scotland is much more improved compared to the one in Greece, where I originally come from. Even though many people would argue that there are many drawbacks, I am sure that the quality of services provided in this country is far better compared with the conditions in Greece. The quality of the services in Scotland was a factor that motivated me to search in more depth how the specific welfare state system works. The second factor that drove me to be involved with such a topic was the experience I gained through my work with people with learning disabilities. I had worked with people who moved to the community after being in long-stay hospitals for many years; this experience led me to understand the difference that could be achieved in peoples' lives and the potentiality of improving the standards of living for the specific group of people. In this framework, I became really interested in searching how services of equal quality could be provided in Greece. The experience that could be gained through de-institutionalisation in Scotland could be of a great value in this attempt.

The choice of the specific type of organisation

The decision to investigate the process of de-institutionalisation in an institution of people with learning disabilities was based on three criteria.

Firstly, organisations similar to the one under investigation are unusual cases. Due to the expansion of the theory of normalisation and the pressure generated by social movements, the services to people with learning disabilities started being provided in

the community. In response to these accumulated changes, the viability of the institutions came into question and actually they led to their closure. In that sense, since the development of the organisation is considered to be its closing down, it consists of an unusual case. Also, the fact that almost all institutions of this kind have already closed down in England and Wales was an additional motivation to be involved in such an organisation. There will not be many more chances for undertaking research in this kind of institutions, in this country; the start of this study was excellent in terms of timing, as the last discharge phase was launched and enabled researcher to be involved in such an organisation. The selected organisation was examined as a single unit.

The second driver for the choice of such an organisation was based on a personal interest and concern regarding the provision of services to people with learning disabilities. As it has already been mentioned, the welfare state in the country of my origin is too weak and inadequate to provide quality services to this group of people. The process of de-institutionalisation of people with learning disabilities is relatively a new concept and only gradual steps have been made towards this practice. It was considered as a great opportunity to investigate the development and implementation of a discharge programme in a more progressive environment, such as Scotland. Through this study, recommendations are made regarding how future programmes of this kind could be improved by the experience gained and lessons learnt through foremost programmes.

The third reason motivated me to handle in such an issue was my personal interest on social workers' participation in this field of practice. Coming from a social work background, I was interested in identifying how social workers are involved in a discharge programme and to what extent their role is differentiated in the two contexts: the institution and the community setting.

The institution under investigation

The area in which the study was conducted had two long stay hospitals for people with learning disabilities. One was a former asylum, which was located far away from

towns and villages and had about 150 patients. The second, which is the one under investigation in this study, was built in the 1960s and from that time had 220 patients. Around the middle of the 1980s the Health Service decided to close the first hospital and to release the money to develop alternatives in the community. An initial plan for this group of 150 patients was drawn up and some of them moved to the community. However, others moved to the newer hospital, which meant that, from the middle of the 1980s onwards, the institution under investigation had almost 300 patients, most of whom were people with learning disabilities and at that time there were no official plans for its closure.

Even though the construction of the hospital can be considered as recent, the regime driving its operation had much in common with the Victorian style of institution. This was evident in the patients' life in the hospital: patients lived in large groups of people in wards and strictly followed a specific daily routine. Their interaction with the local community was limited or restricted, since their needs could be "covered" in the hospital.

Nevertheless, due to a number of factors, including scandals in other institutions nationwide, questions about the effectiveness of institutionalisation, the development of the principle of normalisation, and the emergence of pressure groups and the disability movement, the first attempts at reducing the number of patients in the institution began to be made around the middle of the 1980s. The personal interest of specific key people from the local region constituted the basic drivers for considering other ways of providing services rather than institutionalisation. It was a local rather than a national initiative; there were about three key people, who came together and agreed that people should not live in hospitals. At that time, there was only a small amount of funding available, but it was freed up to develop alternatives in the community. Some people also moved to homes for older people, since there were a lot of older people in the hospital, and other people moved to group homes. Some people moved to their own tenancies, as there were people in hospital who were really able; they could hold their own jobs and look after themselves, and arguably should never have been in hospital. In this way, the motivation of these activists constituted the principal impetus for further changes in this institution.

From that point onwards, the changes became more radical. The overall de-institutionalisation process developed under four different phases and lasted for almost twenty years. The main characteristic of the first two phases was that discharging people were discharged without the benefit of a national policy or an official plan. The third phase was marked by the existence of planning directives from central government. It was during this phase that the majority of patients were moved out of the institution. The last phase of de-institutionalisation was characterised by the discharge of the remaining patients, who turned out to be the patients who needed the most complex care packages to be developed.

Throughout the history of the institution, different dates were set for its closure. One of the first target dates was the end of 1995. After this target failed to be achieved, a four year period of inaction followed, when few or no discharges were made. Subsequently, a new date according to *The Same As You* was set for the end of the year 2005, although subsequently extended to mid 2006, and in fact at the time of writing the institution retains its services for a group of forensic patients. However, the institution now has the form of a community health partnership hospital. This represents progress since Community Health Partnerships (CHPs) are schemes developed by NHS Boards in an attempt to modernise NHS services and also to promote joint services in local communities. The focus of CHPs is to integrate primary care with specialist services and with social care by means of partnerships between health, local authority and voluntary sector organisations, in order to respond to individuals' needs in the local setting.

It can be seen therefore that overall, during this period of almost twenty years, many changes haven taken place regarding the care of people with learning disabilities. In the specific institution under investigation, new policies came in, changes happened regarding structure, various stakeholders surrounded the institution, wards started closing and patients started moving out. In this context, this study aimed to explore professionals' perceptions of how the discharge programme developed, to capture professionals' experience, knowledge and understanding of how a discharge programme could be implemented in a smooth way, and also how best to support professionals to make the transition from the institution to the community.

Purpose of the study

The basic research question that posed in this study was to conceptualize “How was the evolution of the process of de-institutionalisation managed in the specific Scottish institution?” under the wider lens of organisational change. Through the exploration of a specific programme of de-institutionalisation, organisational changes were observed. The fact that an institution ceases its function is a developmental process, since an old model of care is coming to an end. The identification of the policies, practices and procedures which have boosted such a programme can inform future attempts, probably in countries with a less developed welfare state. Moreover, the formation of suggestions and propositions around the progress of a discharge programme can enlighten and drive future programmes in how to proceed with developmental changes with more confidence.

The second research question which was posed was to identify “What factors influenced the way in which professionals adapted to the community setting?”. Through this inquiry the consequences of de-institutionalisation on professionals was examined. The main professional group was social workers. The exploration of how qualified professionals accept possible changes in their work and the extent to which they can adapt (e.g. which new skills might be necessary to develop) were the main inquiries of this study. Through the examination of these themes, the study aimed to identify those elements that could enhance professionals’ adaptation under similar organisational changes.

The structure of the thesis

The current thesis has been divided into four parts. The first part of the study is divided into two chapters. In the first one the focus is placed on the most significant drivers and policies of the last 40 years towards the discharge of people with learning disabilities from long-stay institutions. In the second chapter, the literature review in

the field of organisational changes and the theoretical framework that drives the research are highlighted.

In the second part, the methodology that drove this research is presented. A detailed description is presented regarding the methods of data collection and data analysis adopted.

The third part of the thesis presents the collected data emerging from the study. This part is divided in three chapters, in order to cut down the huge loads of data and allow a better presentation of the themes emerged, under the structure of the three systems that comprise the organisation: the technical system, the political system and the cultural system.

The last part constitutes the discussion of the thesis. The emergent themes are discussed and analysed; also, there is an analysis regarding the implications for theory, policy and practice as emerged through the study. Moreover, an organisational approach in the context of de-institutionalisation is presented; finally, the contribution of this study in the already existing literature is estimated. Suggestions for future research are made at the last bit of this part.